

SD COUNCIL ON DEVELOPMENTAL DISABILITIES – STATE PLAN 2022-2026 SURVEY – Complete Summary of All Surveys

1. Demographic information:

Person with a disability	16
Family member or guardian of a person with a disability	22
Work for a government or community organization that supports people with disabilities	5
Community member	
TOTAL	43

2. Where do you live (city or zip code)?

People with Disabilities

57078	57350	57783
57105 - 2	57401	57785
57110	57580	Unknown
57260 - 3	57702 - 3	

Family Members or Guardians

57005 - 2	57078	57380
57020	57101	57445
57033	57103	57501
57035	57105	57702 – 2
57064	57106	57718
57068	Rural Sioux Falls	57783
57077	57252	

Work for Government or Community Organization Serving PwD

57055	57201	57532
57105	57501	

3. Optional – What is your race?

	PwD	FM	GCO	Total
White	12	19	5	36
Native American	3			3
Black				
Hispanic		1		1
Other				
Did not answer	1	2		3

4. Please check the 5 most important areas from the list below and tell us the barriers you have experienced or why you choose them.

	PwD	FM	GCO	Total
Assistive Technology	1	3	1	5
Availability of community-based services	1	13		14
Childcare		7	1	8
Disability laws and policies affecting people with disabilities	5	2	1	8
Education & Early Intervention		5	1	6
Employment	7	9	2	18
Health	7	4		11
Housing	4	3	2	9
Issues affecting Native American communities (please give specific examples)	1			1
Lack of culturally appropriate services/materials			1	1
Leadership opportunities	2			2
Mental Health	10	2	3	15
Quality of services	4	7	1	12
Recreation/Socializing with friends in the community	7	16	1	24
Self-advocacy and self-determination	4	1	1	6
Supported Decision Making and Guardianship	1			1
Technology – access to computers, internet, training,	2	2	1	5
Transitioning youth from schools to post-secondary education or work	2	4	4	10
Transportation	4	9	3	16

COMMENTS:

People with Disabilities

All of them are very important.

I'm did not have friends at all. I live by myself no help at now. Just – have friends Vast Cable. Pay bill good, ok!

The 1st one I picked is employment that is because I can't find a job that I want and I want to learn more about it. The second one I picked is health and the reason I choose that one is because I have a lot of health issues and I want to learn more about it. The third one I chose is leadership and I choose that one because I want to learn how to become a true leader and I want everyone to become a true leader. The fourth one I picked was mental health and that one I chose because I want to learn all I need to know what to expect with all the mental health issues I got. The last one I picked was supported decision making and guardianship and that one is because I need to learn how to or when I am ready to become my own guardian and not always have to depend on someone else to count on and also when I need to depend on the help from someone.

Currently transitioning to work so top on my mind.

Housing is a big concern of mine. I would like assistance with housing. I want to remain independent, living in my apartment. Technology training for people with disabilities would be

valuable. Basic laptops provided to all with the same training would make it easier. People with disabilities do well with technology!!

Employment most important to earn money, keep busy, self worth and feeling important. Health and mental health to feel good and feel good about myself. Having community friends.

None of them worked for us. State of SD is lousy and do nothing. Don't help. Don't send this portion back to me.

Mental health – bi-polar disorder. Health – having back issues since falling.

Family Members or Guardians

Availability of community-based services –

Support for more in a person's hometown.

Both of my children rely on community services such as LifeScape.

Childcare

Only one barrier and that is childcare – very long list for in-home nursing for children with disabilities.

Respite & day services for adults during Covid.

Aged out of most daycares, limited availability.

Disability laws

These affect every area of life.

Education & Early Intervention

Because these make a life long difference.

Teach about finances, making purchases, writing checks, etc and spending money wisely.

My sons are both involved in special education/early intervention.

Having to fight for integration.

Employment & volunteering to build on natural supports.

Health - It is imperative that my sons have access to quality healthcare due to their many medical needs.

Mental Health – no support groups in area.

Quality of Services - Better pay and more universal training for DSP staff (PIP based would be good).

Recreation/Socializing -

This is quality of life.

Not anything to do, only have theater not open now.

Build natural supports

Due to social distancing – yet recreation goals won't allow anything that doesn't include peer interaction.

Transportation – is provided to and from school.

Our sons are living in a group home. Before Covid-19 they went to an adult day program where they intermittently had the opportunity to work doing piece work (getting paid per item instead of per hour). Since March 13, 2020 they had no day program, no work, just sheltering in place a group home with residents and staff. With more training they could do more meaningful and productive work in the community. Had they had more access to technology, they could still interact with friends and family over Zoom, phone, internet, etc instead of just being isolated in a group home.

Lack of supportive services when older child has aggressive behaviors and needs childcare. We've had to reduce hours at work in order to be with our child before school and after school. Here 4 Youth has become a poor supportive service since I was told my child could no longer be there due to aggressive behaviors – they were not willing to work with the school and parent on behavior plan.

In my opinion these are the most important issues my daughter faces. (availability of community-based services, employment, recreation, self-advocacy and transportation). Her greatest limitation to recreation and socializing in the community is related to lack of independent transportation and having to rely on others for rides. Due to Covid-19, employment is an issue right now.

My son is Type 1 Diabetic with rigid dietary and medical needs. He has no peers or support people who share his same needs for healthy eating and medication management. He is not employed due to his high level of support required in the workplace. The Day Services program is crowded and would not provide the close monitoring he needs. He spends nearly all of his time with family members even in non-Covid times.

Barriers: Need to find companion care providers. No age-appropriate activities set up to socialize with friends. No transportation available.

Respite care program needs to be revamped. It's very hard to find people willing to take care of children with disabilities and pay them a reasonable amount. The budget given to families is inadequate amounts. I have been speaking my thoughts on respite for 10 years. Maybe explore how neighboring states do their program. SD is poor and need improvement.

Barriers are lack of time and money to provide supports. Also a need for creative ways to build natural supports.

Work for Government or Community Organization Serving PwD

Assistive Technology - Most youth do not get the opportunity to assess the options available – school staff do not look into this.

Disability Laws - Everyone thinks ADA but there are many other Acts/Documents that apply as well. Very confusing, different terms for same things, hard to get it correct.

Employment - All people should have this opportunity. Schools are not focused on this as much as they are on academics. Should be a balance with trained staff.

Lack of affordable housing.

Lack of culturally appropriate services/materials - Lots of English publications – lacking in other languages and cultural sensitivity.

Mental Health - Still something to hide, need more providers!

Mental health - More awareness and training in this area. Many people with I/DD deal with this and it is not identified.

Quality of services at CSPs

Self-advocacy and self-determination - Very important for all students/adults to understand and obtain these skills – drives the services for them (I would add PCT to this).

Technology – lack of education.

Transitioning Youth - Many programs but youth still seem unprepared to leave school.

Transitioning Youth - All areas fall into this – effective transition planning and supports will enhance all these areas. This includes some of the issues affecting Native American communities.

Transportation - Always a problem, especially rural.

Transportation is too expensive, flexibility

5. Is there a service available in your community that you or your family member(s) need, but is not accessible due to cost, eligibility, or other reason?

People with Disabilities	<u> 4 </u>	YES	<u> 5 </u>	NO
Family Members/Guardians	<u> 7 </u>	YES	<u> </u>	NO
Gov't or Community Organization	<u> </u>	YES	<u> 3 </u>	NO

If yes, please explain:

People with Disabilities

Before Covid-19 but now my Western Resource person cannot come to my house. They are not doing house calls. I need paperwork assistance.

I did not get help – as a friend walk away from me!

The reason I said yes is because not everyone will take me in because they don't have onsite nurses. Plus, my grandparents don't have money to place me in a new facility.

Computer training and exercise classes.

Transportation to where Rapid Ride doesn't go to see specialty doctors.

I would like to get membership at wellness center but cannot afford it.

Family Members or Guardians

Too often one must move to get 24 hour service and move 2-3 hours away from home and family so visits are difficult – especially in winter.

Adult Education - Just because our sons didn't receive a "normal" education during their K-12 years doesn't mean that they couldn't still learn new and basic skills during their adult years! This could help them in developing the skills needed for better employment and possibly the skills to leave the group home and into their own home. "normal" people don't stop learning after high school why should people living with a disability not have the same opportunity to learn!

My son is Type 1 Diabetic with rigid dietary and medical needs. He has no peers or support people who share his same needs for healthy eating and medication management. He is not employed due to his high level of support required in the workplace. The Day Services program is crowded and would not provide the close monitoring he needs. He spends nearly all of his time with family members even in non-Covid times.

Technology

No transportation available except by parent.

Adult day services due to Covid.

Swimming lessons, unable to transport due to work schedule.

Work for Government or Community Organization Serving PwD

Childcare

Behavioral support – in home

6. What ideas do you have for the Council to help people with developmental disabilities and their families?

People with Disabilities

It depends on what we are referring to – Ed, Health, Social etc. Over all the most important to me to give the community and people of dif. abilities would be teaching people how they learn and how to self-advocate for themselves and others. How cannot. 😊

Well for the people with disabilities I want to help them to stand-up for themselves and show them they don't have to be scared of their disabilities or shy.

Make it easier to work with home medical businesses.

Help people find jobs and live independently.

I know so much will help family, people with disabilities, like find my services.

Lacked all ideas help us people with disabilities.

To let them experience more freedom.

With more fun things to do; bowling.

Explain my disabilities and how I have overcome them to be an effective member of the community.

Family Members or Guardians

Teach/educate on finances and driving a vehicle.

The most important thing is to listen. People will tell you what they need when asked.

Helping families learn how to access and utilize the services that are available in their community is extremely important. We can also help by organizing a fundraiser to donate money to businesses that assist people with disabilities.

Promote age appropriate social interaction activities.

Try to get basic similar support in all communities. There are huge differences depending on where you live.

Better support to families that have children with aggressive behaviors when child still living at home. Only choices are to send child to group home to complete school or parents have to reduce hours at work.

Help locate qualified support people.

Help find supports and transportation.

The mental health availability for people with special needs is nearly non-existent.

Revamp respite care program.

Training on how to build connections for family members or how family members can help individuals.

Work for Government or Community Organization Serving PwD

Tired of conferences for people that work with people with DD without including them. Need to find ways to have them involved, present, attend.

Support group for PwD to cope with loss.

Collaboration with schools and agencies to identify strategies to developing individualized case management services for our youth and families. Services and supports and resources are plentiful ... need assistance in navigating the system and challenging the system to obtain the right services/supports. Ensure academics/functional skills are developed.

Continue to be a great resource to all.

VR services that are more streamlined.

Educate them on different programs – Family Support, Money Follows the Person, Dakota @ Home

7. What self-advocacy activities would you like the Council to focus on or do?

People with Disabilities

How to activities. Come up with games and activities around the community that would challenge persons in a real way now to speak out and educate others at the same time with what they need and why.

I want them to focus on their disabilities and I want them to have fun with all the things we learn.

Speakers in our local area.

Meeting people and get friends.

Workshops on how to overcome the stigma of having a disability.

Family Members or Guardians

Partners in Policy is a good start.

Continue self advocates for change outreach activities.

Adult education and more meaningful job opportunities for people living with disabilities.

Job interview training

Community volunteer opportunities

Training on how to build more connections in the community by being involved by volunteering or working.

Work for Government or Community Organization Serving PwD

Would like to see promotion of PwD being included on boards and committees, but not just as tokens.

Again, this is important – collaborating with schools and service agencies to identify strategies to ensure all youth get an opportunity to get training on self-determination skill development, which includes self-advocacy skills.

Under employment and adult independence

Choices

Teach individuals to know their rights, what benefits/medical insurance they have and what their money is spent on.

8. Any additional comments

People with Disabilities

Teaching is empowering when you are learning that task or lesson.

Help do my green yard work.

None of the stupid questions. Don't ask me any of these. How many of these questions am I going to answer. Please don't send more questions!

We never got tested Covid-19 because you refused to test Native Americans on the reservation, and you made North Dakota DOH do SWOLTR and you neglected my health for 2 months.

State of SD didn't help us when we had problems, please don't repeat any Covid questions.

I hope you help with that please (meeting people and getting friends).

Family Members or Guardians

Family Support from VOA has been best support services for my child. We do receive companion care services from VOA since child is older but does not make up for wages lost from full time work.

We have pretty much given up. Everything we ask about we get told "no". The paperwork to get approved for a person to provide supports is huge and too much for most people. There is nobody to help them fill it out. I usually end up paying the support person out of my pocket. If this could be streamlined it would help a lot. If you have further questions you can contact me. Dee Gustaf, 605-254-7635

Supporting families with schools who deny assistance for students to access care with mental health. Support families who have a student with a disability – schools don't want to help, which creates more problems for the families.

Consider looking at other alternatives for respite care. It's difficult to hire people and pay them a decent wage for what they have to do. Increase funds for families. It's cheaper to keep kids in their homes than put them in a care facility. They deserve to be at home with their families.

Work for Government or Community Organization Serving PwD

Identify strategies that will enhance opportunities for middle and high school students to enroll and participate in CTE classes with supports.